

Children with Special Health Care Needs and Disasters

Volunteer Summit

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Objectives

Discuss vulnerability of children with special health care needs (CSHCN) in disasters/threats.

Describe pre-event disaster planning strategies for CSHCN.

Identify emergency support services for CSHCN during disasters/threats.

Official Definition of CSHCN

CSHCN are defined by the Department of Health and Human Services, Maternal and Child Health Bureau (MCHB) as:

“...those who have or are at increased risk for a chronic, physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

Children with Special Health Care Needs (CSHCN)

- Children
 - 80 Million in US (25% of population)
 - 12 million have a special health care need
- LA ranked 26th in U.S. for CSHCN—14.8% (pre-Katrina ranked 2nd)
- About 45% of CSHCN in LA are publicly insured

Vulnerability of CSHCN in Disasters

- Health care challenges
 - Differ from adults
 - Dependent on caregiver
- Access to pediatric medical services & supplies
 - Pediatric medical services (*PCPs, subspecialists, nurses, therapists, social workers, etc*)
 - Healthcare facilities (*hospitals, clinics*)
 - Medical records

Vulnerability of CSHCN in Disasters

- Disruption in routine
- Coordinating care
- Emotional trauma
- Adequate evacuation transportation
- Adequate evacuation accommodations

Vulnerability of CSHCN in Disasters

- Safety
- Separation from family
- Sheltering concerns--cribs, high chairs, peds-friendly bathrooms, toddler foods
- Transportation—appropriate car seat for CSHSN
- Environmental hazards post-disaster—lead, mold, etc

All Hazards Planning for CSHCN

- Determine a plan to incorporate disaster readiness into practice (*how/when to talk to families*)
- Promote Family All Hazards Plan
 - AAP (*American Academy of Pediatrics*): Emergency Information for CSHCN
 - Family Voices
 - Louisiana DHH Newspaper/Brochure
 - HRSA (*Health Resources & Services Administration*)

All Hazards Planning for CSHCN

Health Care Provider Opportunities

- Help family:
 - Keep medical information organized and ready for evacuation
 - determine emergency preparedness needs
- According to Needs of Child
 - Contact utility company
 - Maintenance of medications/equipment
 - Training family members to assume role of in-home health care provider
 - Access to important emergency phone numbers

All Hazards Planning for CSHCN

- Post-disaster planning
 - Best time to think/talk about this is before an event
 - What must the family consider before returning after an evacuation?
 - What are this child's specific needs?

Family Emergency Preparedness Plan

- Register with local/regional Emergency Operations Center (EOC) and Emergency Medical Service (EMS)
 - Helps identify number of medically fragile and technology children and plan for services needed
- Plan for evacuation transportation & accommodations

Family Emergency Preparedness Plan

- Encourage well child care—according to AAP schedule
 - Reduces number of hospitalizations before and during disaster
 - Immunizations
 - Anticipatory guidance/teaching

Evacuation/Shelter for CSHCN

- Private—home, hotel, etc
- Hospital based shelter
- General Shelter
 - Red Cross
 - Critical Transportation Needs Shelter
- Medical Special Needs Shelter

Admission of CSHCN to MSNS

Same as for Adults

- Caregiver requires assistance with medical care and/or child needs monitoring by a nurse
- Physical or mental condition limits mobility
- Caregiver needs assistance to adequately provide care for child
- Care must be able to be provided in MSNS
- Care cannot be provided in a general population shelter

CSHCN in MSNS

- Frequently, different diagnosis types than for adults
- MSNS section for children

MSNS not for some CSHCN

- Children on ventilators
- Urgent medical support needed
- Acutely ill/contagious
- Immunodeficiency
- Receiving IV medication

This population of CSHCN will be triaged and sheltered elsewhere

Possible CSHCN MSNS Admissions

- Medical conditions:
 - Airway-- asthma; tracheostomy
 - Pulmonary—cystic fibrosis
 - Neurological—cerebral palsy; seizure disorder
 - Emotional/behavioral—autism
 - Musculoskeletal—spina bifida; muscular dystrophy
 - Endocrine—diabetes
 - Sensory—low vision; blindness; hearing loss
- Mobility issues—wheelchairs, walkers, crutches

Equipment Requiring Electricity for CSHCN

- Feeding pumps
- Nebulizers
- Oxygen concentrators
- C-Pap machines
- Suction machines

MSNS Medical Assistance for CSHCN

Caregiver may need assistance with:

- Medication administration—oral, injections, via tube
- Catheterization—CIC
- Suctioning and trach care
- Glucose testing
- Vital signs
- Dressing changes
- Skin checks
- Turning/positioning

Tips for Working with Persons with Developmental Disabilities in Emergency Situations

- Simple explanations
- Regular routine
- Support family/caregiver to stay with child
- Introduce them to alternate caregiver, when needed
- Keep in area with least stimulation
- Explain MSNS or other site
- Provide comfort food
- Limit choices

Resources within MSNS for CSHCN

- Staff with experience in working with CSHCN
 - Nurses
 - Social Workers
 - Nutritionists
- EMS
- Medication/Oxygen
 - Over the counter (OTC) pediatric medication formulary
 - Oxygen—managed by EMS

Resources within MSNS for CSHCN

- Methods to obtain pediatric medication & DME
 - Medicaid/insurance
 - Assistance in obtaining medication for uninsured
 - Local resources
- Essential supplies—diapers, formula, food
- Equipment available from regional OPH Safety Coordinators
 - Pack N Play travel cribs
 - Car seats
 - Pediatric toilets

Assessment of Care Needs for CSHCN in MSNS

- What caregiver may have:
 - AAP Emergency Information Form
 - Medical records
 - School information—IFSP; IEP
- Important information to obtain:
 - Usual state of health
 - Routine schedule
 - Activities of daily living (ADLs)
 - Special needs or precautions
 - Supplies, equipment, medication

Assessment of Care Needs for CSHCN in MSNS

- Caregiver Needs
 - Rest/sleep/other
- Child needs
 - Psychosocial assessment
- Discharge Planning
 - Starts at admission

Care for CSHCN in MSNS

May be affected by:

- Age
- Developmental stage
- Social needs
- Emotional needs
 - For themselves
 - Highly influenced by caregiver
- Motor skills—ambulation, feeding, dressing

Care for CSHCN in MSNS

- Communication—ability to talk or understand
- Culture
- Supervision/protection:
 - Hazards
 - During caregiver rest and personal time

Long Term Sheltering for CSHSN

- Continuity of Services
 - Therapy
 - School
 - Play

Agency Support for CSHCN in MSNS

- Department of Social Services
- Office for Citizens with Developmental Disabilities
- Office of Mental Health
- Others

Service coordination through MSNS social services staff

Community Resources for CSHCN/Family Support

Families Helping Families

- Resource centers for individuals with disabilities/families in all 9 regions of LA
- Provide resources, information, referrals and support

Social service staff in MSNS can provide coordination with this agency.

Disaster Recovery for CSHCN

- Connection to Vital Resources
 - Medications/equipment/supplies
 - Pharmacy
 - PCP/specialists
 - Home Health
 - Personal Care Attendants
 - School/support staff
 - Transportation
 - Family/friend support
- Consider possible environmental hazards
- Resumption of normal routine

Emergency Response for Children/CSHCN for Catastrophic Health Event/threat

- Biohazard Response—Tamiflu and doxycycline is dosing ranges for pediatrics
- Chemical Response—pediatric auto-injectors for atropine
- Mass casualty—contract for cache of drugs and pharmaceuticals that includes pediatric dosages

Resources/Websites for CSHCN and Disasters

- AAP: <http://www.aap.org/>
- DHH/OPH/Center for Community Preparedness: <http://www.dhh.louisiana.gov/offices/?ID=218>
- Family Voices: <http://www.familyvoices.org/>
- See other websites on Family Voices Emergency Preparedness Plan
- Red Cross: <http://www.redcross.org/>
- Families Helping Families (9 offices statewide)—all have websites